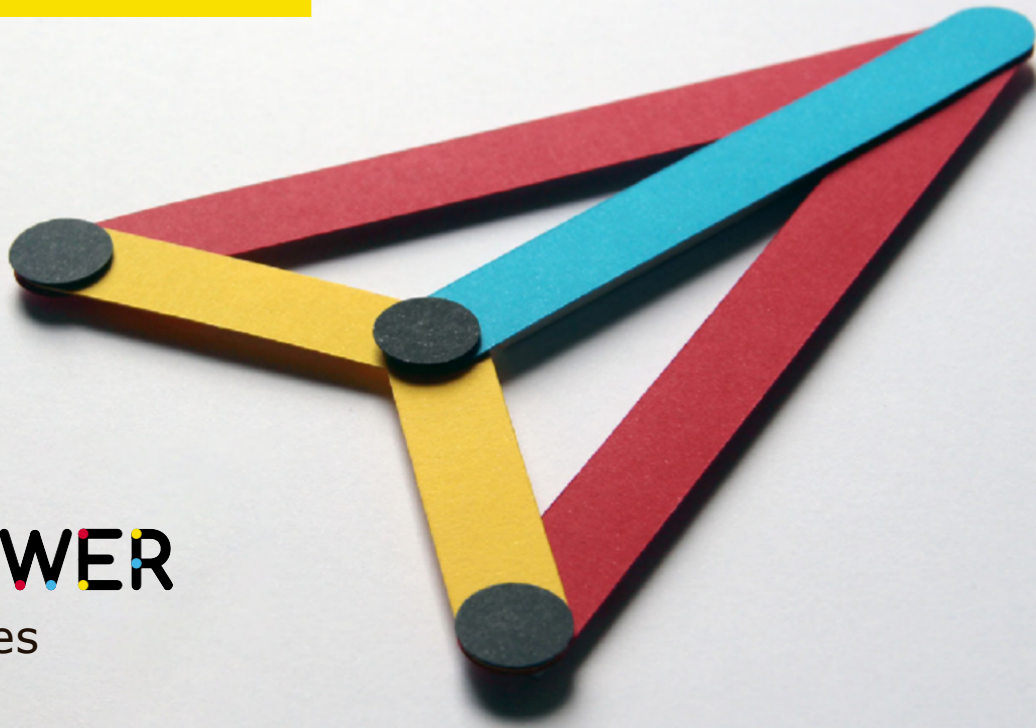


D5.1

**EMPOWER**  
deliverables



Deliverable name

Evaluation and improvement

Type

R - Document Report

Dissemination level

PU - Public

Date



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A report that specifies the first observations and experiences of WP researchers and stakeholders while using the ethical framework, as well as the recommended additions and improvements. This deliverable consists of two parts: a) a specification of a framework for the analysis of the notion of 'empowerment', and b) a specification of the methods and procedures involved in supporting the consortium members and the main stakeholders in their reflection about how the consortium's work supports the empowerment of neurodiverse children.

Description

WP.5.1

Work Package. 5

Lead Beneficiary – RU

# Ethics Report

Date	Version	Description	Authors
28.10.2023	1.0	<p>A report that specifies the first observations and experiences of WP researchers and stakeholders while using the ethical framework, as well as the recommended additions and improvements.</p> <p>This deliverable consists of two parts: a) a specification of a framework for the analysis of the notion of 'empowerment', and b) a specification of the methods and procedures involved in supporting the consortium members and the main stakeholders in their reflection about how the consortium's work supports the empowerment of neurodiverse children.</p>	Pim Haselager & Thomasin Coggins

## a) The Framework

### Introduction

Artificial Intelligence provides both opportunities and threats in many fields, but certainly also in the field of education (e.g., Humble & Mozelius, 2019; Webb et al. 2021). Moreover, the AI Act considers education to be a field where the use of AI can be considered as 'high risk' (EU AI Act, 2021, e.g. preamble (35) and Annex III), with many considerations, constraints and quality standards, regarding human oversight, transparency & information, robustness etc. This makes the usage of AI in the context of education of neurodiverse children with the aim to empower them a topic of specific ethical concern.

Attempting to use AI to empower individuals can easily lead to misunderstandings and contribute to or produce ethically challenging situations. Ultimately, technology does not empower people. Instead, people become empowered via complex socio-political processes, potentially through their use of technology (Constanza-Schock, 2020; D'Agnazio and Klein, 2020; Swierstra, 2015). Indeed, without proper human oversight, creating technology that ostensibly empowers already marginalised or vulnerable groups may have unforeseen, potentially adverse effects (Keyes, 2020; van de Poel, 2016). Additionally, we must recognise that empowerment requires communal effort and often demands that non-marginalized people (potentially including parents, teachers, and researchers) reflect upon how their actions and beliefs can unintentionally reproduce or reinforce ideas and practices that leave some people worse off than others (Hill Collins, 2000; McGuire, 2016).

Empowering these stakeholders (parents, teachers, and researchers) may require them to question how they perceive and interact with neurodiverse people. For instance, studies show that autistic people develop strategies to help them feel safe and comfortable in stressful contexts due to their heightened sensory responses to stimuli (e.g., lights and sounds). These strategies include repetitive behaviours or self-stimulatory actions ("stimming"), which allistic people often interpret as unusual or abnormal. (Spiel et al., 2019). Considering that these strategies help people within the autistic spectrum block out distracting stimuli and focus on tasks, accommodating them (e.g., via design, education, and interpersonal communications) within the research proposed by the Empower Project will enable its key stakeholders to co-create technologies which meet their collective needs. There are many other examples of behaviours neurodiverse people develop to cope with situations they find distressing or distracting, which we should consider when designing

technologies meant to help improve educational practises for neurodiverse children, their parents, and teachers. WP 5 is investigating how we can identify, properly discuss, and design for needs of this kind while continuously evaluating whether such work does, indeed, empower the project's key stakeholders.

## The Framework

**A.** The framework specified here aims to **clarify the meaning of empowerment** in the context of the education of neurodiverse children. It addresses a) who exactly will be empowered, 2) in what ways, 3) by which technologies, 4) to achieve exactly what, and 5) how such achievements can be measured.

**B.** The WP has developed and applied **methods for stimulating reflection** by consortium members regarding the goals, methods, and results of the project, and it will continue to refine them in the light of results and feedback received. The methods have been derived from literature analysis regarding the notion of empowerment, its applications in the context of education, presentations of the main points and issues identified in the literature, and discussion sessions with members of the consortium, as well as the preparation for and analysis of the results of feedback sessions with main stakeholders.

**C.** Based on the framework, WP 5 is 1) **investigating potential possibilities, risks, and concerns** and 2) **suggesting recommendations** for design and application (including training).

**D.** The first **drafts and results** were **discussed** online and through email throughout the first year and presented at three on-site meetings in Valencia (October 17/18, 2022), Nijmegen (March 27/28, 2023) and Cluj-Napoca (September 25/26, 2023). This has led to 1) systematic discussion with project members and stakeholders about the suitability of the methods and implementations developed, 2) feedback on the suitability of the WP5's intermediate results, and 3) identification of topics requiring further clarification by WP5 (e.g., what works, what needs improvement, and overall, how can WP 5 further help the project meet its goals).

## Intermediate results

### Part A, Framework

Although philosophers, sociologists, and political theorists have long debated the meaning of empowerment, its definition and how we can ensure its realisation remains unsettled (see below). Additionally, precisely how technology could help empower people is an open question.

As such, the major aim of the framework of WP5 on Ethics is to clarify the notion of empowerment, in general, and regarding the development, design, and deployment of educational technologies created for neurodiverse children. Therefore, WP5 is synthesising empirical, conceptual, and practical insights gathered from the other work packages' research and relevant literature concerning the meaning of empowerment. Overall, WP5 is translating its research output into methods for stimulating the consortium's reflections on when, under what conditions, and to what extent AI technology supports the empowerment of the main stakeholders (children, teachers, parents). More specifically, it is helping to clarify exactly how game development, data collection and AI data analysis is and could contribute to empowerment (see figure 1). Over the last year, i.e., the first year of the project, a framework has been developed and discussed in interaction with the other WPs of the Empower consortium, to approach this subject.

The World Health Organization defines empowerment as “a process through which people gain better understanding and control over their lives” (Baumann, 2010). Ideally, technology supports such a process, and stimulates increased self-understanding and self-determination. Self-understanding is, in its most basic, dictionary sense (Merriam-Webster): knowledge or understanding of one's own capabilities, character, feelings, or motivations. Self-determination is defined as “volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life” (Wehmeyer, 2005, p. 17). Self-determined agents serve their chosen goals and understand the relationship between their actions, the means involved, and the outcomes they experience (Little & Lopez, 1997; Shogren, Wehmeyer, Palmer, et al., 2015, p.258).

As the original proposal specifies, the EMPOWER consortium aims to empower 1) neurodiverse children 6-9 years old by 2) helping them to develop their executive control and emotional self-regulation, through 3) playing computer games and providing them (as well as their teachers and parents) with feedback based on AI analyses of the collected data. It is expected that 4) playing these games and receiving feedback will strengthen their executive control and emotional self-regulation.

## Games

**Continuous performance**  
**Working memory**  
**Cognitive flexibility**  
**Delay of gratification**  
**Emotion naming**  
**Emotion intensity rating**  
**Emotion understanding**  
**Emotion regulation**

## Data

**Eye tracking**  
**Wearables**  
**Performance**  
**Interviews**  
**Etc.**

## AI

**Analyses**  
**Profiles**  
**Changes**



## Empowerment

**Executive control & Emotion regulation**  
**self-determination, self-esteem**

*Figure 1: From Games, Data & AI to Empowerment*

In relation to the notion of empowerment, there are further questions that have been formulated to increase reflection of the consortium regarding its overall goal (see section B2).

## Intermediate results

### Part B, Methods

In terms of methods for increasing reflection, in its first year, WP5 has focused on two main issues: concepts and questions. Ethical analysis regarding the use of AI in sensitive domains (such as care or education) can make use of a so-called 'ethical cycle' (van de Poel & Royakkers, 2011; but see also van de Poel, 2020; and Benin& Kudina, 2020 for attention on the dynamic aspects of such a cycle) and the Value Sensitive Design approach (e.g., Friedman & Hendry, 2019; Winkler & Spiekermann, 2021).

The tripartite methodology of value-sensitive design starts out with conceptual investigations of central issues regarding the application of technology, then involves empirical investigations of the human context in which the technology is situated, and then provides recommendations for the design of technology. The ethical cycle provides a basic, orienting tool for structuring and improving moral decisions by supporting a systematic analysis of the moral problem.

It starts by identifying the main concepts involved in the statement of a potential moral issue (phase 1), and identifies the main stakeholders and actors involved, their main interests and the relevant moral values (phase 2).

In this method section, we will focus on specifying these two first 'phases' of the ethical cycle before specifying the options for action (phase 3) and the ethical evaluation and reflection (phases 4 and 5).

It is important to realise that the ethical cycle is a useful tool to systematise reflection, but in practice, hardly, if ever, is followed in a completely step-by-step fashion. In practice, adopting such a cycle approach means going back and forth to the various phases and issues and, while doing so, continuing to deepen the communication and shared understanding of the issues involved and the potential solutions available.

As Boenink & Kudina (2020, p. 450) say, values are "lived realities, interactive and dynamic"; hence, the process and results require continuous reflection, communication, and potential reinterpretation. For this reason, we report in an appendix the results of three separate meetings with members of the other WPs to discuss the ethical framework in more detail (see also 'Part D, Drafts, results & discussions' below). For the same reason, we expect to come back to certain issues discussed here in future deliverables.

## B1), Concepts

In addition to the analysis of the consortium's central notion of 'empowerment' (see Part A above), a primary conceptual moral issue concerns how we speak and write about neurodiverse people as that contributes to a discourse that can shape societal perceptions of them (D'Ignazio and Klein, 2020; Hill Collins, 2000). Additionally, it can and often does influence how neurodiverse people perceive themselves (Hacking, 2009). Historically, such discourse has tended towards describing neurodiverse people, especially children, as being abnormal and expressing traits that deserve rectification, often via medical or educational interventions (McGuire, 2016).

Even today, many organisations and individuals who wish to help neurodiverse children discuss autism and attention-deficit disorder as though these conditions were diseases we should attempt to cure or even eradicate (McGuire, 2016).

The sociological literature on neurodiversity contains many other examples of language-use reinforcing ideas that stigmatise neurodiverse people's experiences and needs (e.g., portraying them as deviant or pathological) (Goffman, 1963; Keyes, 2020). Suppose we wish to empower the project's key stakeholders. In that case, we must acknowledge that the language we use as researchers matters and can reproduce discourse that makes it harder for children, teachers, and parents to coordinate with one another. For instance, many people diagnosed with NDDs now prefer to identify as neurodiverse to address the stigma associated with being medically differentiated from the rest of the population (Armstrong, 2010; Botha et al., 2021; Bottema et al., 2021; Bury et al., 2020; Dwyer et al., 2022 Sinclair, 1993; Singer, 1999; Vivanti, 2020). Of course, identifying potentially sensitive language requires vigilance and research.

This is very much an ongoing debate, not just because of various ways of interpreting words or labels by different groups (Kenny et al., 2015) or because of cultural differences (Keating et al., 2022). It is, after all, one thing to emphasise that certain differences are not deficiencies but rather illustrate human neurodiversity that could be celebrated (Bury et al. 2020; Botha et al., 2021; Bottema et al. 2021; Vivanti ob.cit.,).

But it is something else to deny, explicitly or implicitly through language, the severity of problems that some people might experience, and that could lead to trivialising the seriousness of a condition or lead to a reduction in the support that people might need (Singer et al. 2022). As such, WP5.

Will continue to provide means for the consortium to reflect on language use and continuously consult the growing body of literature on this subject to support that the project's internal and external communications, ideally, exemplify best practices regarding the representation of neurodiverse people.

## B2), Questions

As specified in the framework above, the work of the consortium is based on the expectation that playing computer games, acquiring data, and providing AI-based feedback to children, teachers and parents will help to strengthen children's executive control and emotional self-regulation.

But in itself, this leaves open a more general question, specifically, how does increased executive control and emotional self-regulation, as measured through performance on computer games, relate to the broader notion of empowerment, and in what way?

Potential candidates to be examined here include the school participation and results of the children involved, improvement in their capacity for self-understanding, as well as their self-esteem, and increase in class enjoyment, as indicated by themselves, their parents



and their teachers.

First, conversations with the stakeholders have been held in the language of the people involved by local researchers. These preliminary findings, as well as the usability of e.g. the Rosenberg Self-Esteem scale (Monteiro et al., 2022; Syropoulou et al., 2021) will be further discussed in a special online session in October 2023, with the WPs 2, 3 & 6 (see also section D below).

As a consequence of that session, it has been decided to focus on the available data from the usability questionnaire for children. Although these data are still being analysed, the focus on user experiences (Was the game interesting? Do you feel good about playing this game? Would you like to play it frequently? Did you do well? etc.) fits well with the notion of empowerment. To be sure, the primary target group of the empower project are neurodiverse children aged 6-9 years, who are still in the process of developing their capacity for self-determination (Sands & Wehmeyer, 1996, pp. 8-9).

Therefore, the question is not whether full-blown empowerment has been achieved but rather to what extent the technology developed and applied in this project stimulates a development towards increasing self-determination. Moreover, neurodiverse children require technology that is specifically directed at their cognitive profiles. UNESCO has proposed that by providing opportunities for personalised learning at scale, AI could contribute to achieving Sustainable Development Goal 4: ensuring an inclusive and equitable education and promoting lifelong learning opportunities for all (Pedro et al., 2019; Institute for Ethical AI In Education, 2020).

Hence, the ultimate question is how AI technology can support inclusive and equitable educational practices such that the development of self-determination is supported and stimulated.

## Intermediate results

### Part C, Possibilities, risk & [check] Concerns & Opportunities Come back to AI in general & automation bias

Following the aims of the proposed framework, Work Package 5. has already conducted preliminary studies on the risks the consortium may face whilst conducting research involving neurodiverse children via a literature review of mostly, sociological scholarship concerning how the scientific community has, historically, viewed and treated disabled people. We have translated these concerns and opportunities into three research areas that WP5 will explore further to provide the consortium with means to reflect upon their research.

#### C1, Individualization of disability

Western and Westernized societies generally individualise disability (Oliver, 1990). Traditionally, disabled people have been treated as though their impairment(s) disadvantage them or create obstacles they must endure as individuals. In short, they have been considered to be disabled by their impairment(s), whatever those impairment(s) may be. Since the 1980s, disability studies scholars have critiqued this prevalent viewpoint and argued that we should recognise that people become disabled when their social and physical surroundings do not accommodate their impairment(s) (Criado Perez, 2019; Oliver, 1996; Winter, 2003). For instance, many neurodiverse people are hypersensitive to sounds, smells, and lights thus have trouble concentrating in environments neurotypical people would perceive as unremarkable (de Vries, 2021; Panagiotidi, Overton & Stafford, 2018). Unfortunately, many spaces we enter throughout our daily lives do not suitably accommodate neurodiverse people as they include social or physical distractions (e.g., people talking over each other or fluorescent lights) that distress them. This is a collective rather than an individual problem. We cannot generally assume, as a society, that people will respond to stimuli as neurotypical people do and thereby neglect neurodiverse people's needs.

More recently, researchers and legal bodies (including the European Union) have affirmed that disabled people deserve to "benefit from measures designed to ensure their independence, social and occupational integration and participation in the life of the community" (Charter of Fundamental Rights of the European Union, 2012, Article 26). Such measures include the provision of educational tools, methods and facilities that support disabled people's needs and enable them to have equal access to all levels of education (UN General Assembly, 2007; Degener, 2017; Shaw, 2014). This provides an important

possibility for the Empower Project to improve communications between neurotypical and neurodiverse people (Spiel et al., 2019).

## C2, Knowledge consolidation

Historically, marginalised groups, including neurodiverse people, have had little influence on how the scientific community studied and interpreted their experiences (Harding, 1991; Namaste, 2000). This way of doing science means that the theories and data we use today often do not represent marginalised peoples' actual experiences but scientists', often value-laden, interpretations of them (Harding, 1995). Hence, for instance, many social scientists contend that we should incorporate marginalised people's perspectives and knowledge into scientific discussions, especially if we intend to conduct research that involves or affects them (D'Ignazio and Klein, 2020; Hacking, 2009; Hill Collins, 2000; Namaste, 2000). As the Empower Project will study neurodiverse children, communication can pose a challenge, although there are methods available to gather insights from children (Hutchinson, 2021; Shogren, Wehmeyer, Palmer, et al., 2015), and the questionnaires used provide clear and useful answers. Hence, WP5 will continue to work closely together with WP2, WP3 & WP6 to develop means to consolidate knowledge generated by neurodiverse persons (via literature reviews and, ideally, consultations with neurodiverse adults who completed their primary education in the European Union) into the project's scientific practices to supply the consortium with suggestions.

## C3, Data Choices

Although the Empower Project complies with the General Data Protection Regulation and, therefore, will respect the data rights of its research participants as defined by EU law, we should not assume that data collection, analysis, and dissemination practices that observe legal standards are ethically sound. Indeed, one may still cause harm and contribute to injustices while following the law, especially when conducting studies involving vulnerable individuals or groups (D'Ignazio & Klein, 2020). For instance, how, when, where, and why researchers choose to collect data on neurodiverse people will impact how neurodiversity is represented within the scholarly literature and may reinforce harmful scientific and societal biases concerning the treatment of members of these communities, including children (e.g., medically, pedagogically, and interpersonally) (D'Ignazio & Klein, 2020; Keyes, 2020; Spiel et al., 2019). WP5 will investigate how researchers can improve their data science practises to account for neurodiverse people's needs without producing scientific findings that misalign with their interests and experiences. We will conduct thorough literature reviews on the ethics and politics of data science to accomplish this goal and continuously share our results with the consortium to help them reflect upon the project's data practices.

## Intermediate results

### Part D, Drafts, results & discussions

The ideas, framework and preliminary results have been presented to all consortium members at the meetings in Valencia (October 17/18, 2022), Nijmegen (March 27/28, 2023) and Cluj-Napoca (September 25/26, 2023).

During the meetings at Nijmegen and Cluj-Napoca, a subgroup of the consortium has been organised, referred to as the 'Ethical Reflection Team' (ERT), consisting of at least one member of all the WPs. The members of the ERT are:

WP1 (Project Management) Gerardo Herrera, gerardo.herrera@uv.es

WP2 (Digital Education) Aristides Ferreira, Aristides.Ferreira@iscte-iul.pt

WP3 (Platform Development) Lucia Vera, Lucia.Vera@uv.es

WP4 (Platform Algorithms) Marcos de Paula Bueno, marcos.depaulabueno@donders.ru.nl

WP5 (Ethics of Technology) Pim Haselager, pim.haselager@donders.ru.nl

WP6 (Platform Impact) Christina Cotescu, christina.costescu@gmail.com

WP7 (Dissemination) Aurelie Baranger, aurelie.baranger@autismeurope.org

WP8 (Ethics Requirements, Gerardo Herrera, gerardo.herrera@uv.es

In October 2023, three separate sessions are planned as digital meetings in order to focus on specific topics:

A) Focus on games & platforms: WP2 (Digital Education), WP3 (Platform Development) & WP6 (Platform Impact)

B) Focus on AI: WP4 (Platform Algorithms)

C) Focus on organization: WP1 (Project Management), WP7 (Dissemination) & WP8 (Ethics Requirements)

The results of these sessions will be made available as additional deliverables, in the form of an appendix to this document.

A suitable candidate for the planned post-doc position for WP5 has been found, Thomasin Coggins. Fortunately, she was already present digitally at the meeting in Cluj-Napoca and contributed to some parts of this deliverable, although the post-doc position can start formally only in January 2024.

## Bibliography

- Armstrong, T. (2010). *Neurodiversity: Discovering the Extraordinary Gifts of Autism, ADHD, Dyslexia, and Other Brain Differences*. Hachette Books.
- Baumann, A. (2010). User empowerment in mental health – a statement by the WHO Regional Office for Europe. <https://apps.who.int/iris/bitstream/handle/10665/107275/E93430.pdf>
- Benin, M. & Kudina, O. (2020) Values in responsible research and innovation: from entities to practices, *Journal of Responsible Innovation*, 7:3, 450-470, DOI: 10.1080/23299460.2020.1806451
- Botha, M., Hanlon, J. y Williams, G. L. (2021). Does language matter? Identity-first versus person-first language use in autism research: A response to Vivanti. *Journal of Autism and Developmental Disorders*, 1-9.
- Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J. y Hand, B. n. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*, 3, 18– 29.
- Bury, S. M., Jellett, R., Spoor, J. R. and Hedley, D. (2020). “It defines who I am” or “It’s something I have”: What language do [autistic] Australian adults [on the autism spectrum] prefer?. *Journal of autism and developmental disorders*, 1-11.
- Charter of Fundamental Rights of the European Union (2012). doi:10.3000/1977091X.C\_2012.326.eng. <https://eur-lex.europa.eu/legal-content/EN/ALL/?uri=OJ:C:2012:326:TOC>
- Costanza-Chock, S. (2020). *Design Justice: Community-Led Practices to Build the World We Need*. MIT Press.
- Criado Perez, C. (2019). *Invisible Women: Exposing Data Biases in a World Designed by Men*. Vintage.
- Degener, T. (2017). A New Human Rights Model of Disability. In: Della Fina, V., Cera, R., Palmisano, G. (eds) *The United Nations Convention on the Rights of Persons with Disabilities*. Springer, Cham. [https://doi.org/10.1007/978-3-319-43790-3\\_2](https://doi.org/10.1007/978-3-319-43790-3_2)
- de Vries, B. (2021). Autism and the Right to a Hypersensitivity-Friendly Workspace, *Public Health Ethics*, 14 (3), pp. 281–287, <https://doi.org/10.1093/phe/phab021>
- D'Ignazio, C. & Klein, L.F. (2020). *Data Feminism*. MIT Press.
- Dwyer, P., Ryan, J. G., Williams, Z. J. and Gassner, D. L. (2022). First do No harm: Suggestions regarding respectful autism language. *Pediatrics*, 149(Suppl 4), e2020049437N.
- EU AI Act (2021) *Proposal for a regulation of the European Parliament and of the council laying down harmonised rules on Artificial Intelligence (Artificial Intelligence Act) and amending certain union legislative acts*. <https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX:52021PC0206>
- Friedman, B., & Hendry, D. G. (2019). *Value sensitive design: shaping technology with moral imagination*. Cambridge, MA. MIT Press.
- Goffman, I. (1963). *Stigma: Notes on the Management of Spoiled Identity*. Penguin.
- Hacking, I. (2009). How We Have Been Learning to Talk About Autism: A Role For Stories. *Metaphilosophy* 40(3-4).
- Harding, S. (1991). *Whose Science? Whose Knowledge? : Thinking from Women’s Lives*. Cornell University Press.
- Harding, S. (1995). “Strong objectivity”: A response to the new objectivity question. *Synthese* 104: 331-349. <https://doi.org/10.1007/BF01064504>
- Hill Collins, P. (2000). *Black Feminist Thought*. Routledge.
- Humble, N., & Mozelius, P. (2019). Artificial intelligence in education—A promise, a threat or a hype. In *Proceedings of the European conference on the impact of artificial intelligence and robotics* (pp. 149-156).

- Hutchinson, L.R., Perry, N.E., & Shapka, J.D. (2021). Assessing young children's self-regulation in school contexts. *Assessment in Education: Principles, Policy & Practise* 28(5-6): 545-583. 10.1080/0969594X.2021.1951161
- Institute for Ethical AI in Education (2020). The ethical framework for AI in education. <https://www.buckingham.ac.uk/wp-content/uploads/2021/03/The-Institute-for-Ethical-AI-in-Education-The-Ethical-Framework-for-AI-in-Education.pdf>
- Keating, C. T., Hickman, L., Leung, J., Monk, R., Montgomery, A., Heath, H. y Sowden, S. (2022). Autism-related language preferences of English-speaking individuals across the globe: A mixed methods investigation. *Autism Research*. <https://doi.org/10.1002/aur.2864>.
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C. y Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442– 462.
- Keyes, O. (2020). Automating autism: Disability, discourse, and Artificial Intelligence. *The Journal of Sociotechnical Critique* 1 (1). 10.25779/89bj-j396
- Little, T.D., & Lopez, D.F. (1997). Regularities in the development of children's causal conceptions of school performance. *Developmental Psychology*, 33, 165–175.
- McGuire, A. (2016). *War on Autism: On the Cultural Logic of Normative Violence*. University of Michigan Press.
- Merriam-Webster Lemma on Self-understanding <https://www.merriam-webster.com/dictionary/self-understanding>. Accessed 18-7-2023.
- Monteiro, R.P., Coelho, G.L.d., Hanel, P.H.P. et al. The Efficient Assessment of Self-Esteem: Proposing the Brief Rosenberg Self-Esteem Scale. *Applied Research Quality Life* 17, 931–947 (2022). <https://doi.org/10.1007/s11482-021-09936-4>
- Namaste, V. (2000). *Invisible Lives: The Erasure of Transsexual and Transgender People*. University of Chicago Press.
- Oliver, M. (1990). *The Politics of Disablement*. MacMillan Publishers Limited.
- Oliver, M. (1996). *Social work: disabled people and disabling environments*. Kingsley Publishers.
- Panagiotidi M., Overton, P.G., Stafford T. (2017). The relationship between ADHD traits and sensory sensitivity in the general population. *Compr Psychiatry*, ;80, pp.179-185. doi: 10.1016/j.comppsy.2017.10.008. Epub 2017 Oct 25. PMID: 29121555.
- Pedro, F., Subosa, M., Rivas, A., & Valverde, P. (2019). Artificial intelligence in education: challenges and opportunities for sustainable development. ED-2019/WS/8, <https://unesdoc.unesco.org/ark:/48223/pf0000366994>
- Sands, D.J., & Wehmeyer, M.L. (1996). *Self-determination across the life span: independence and choice for people with disabilities*. Brookes Pub. Co.
- Shaw, B. (2014). Inclusion or Choice? Securing the Right to Inclusive Education for All. In: M. Sabatello & M. Schulze (eds) *Human Rights and Disability Advocacy*. University of Pennsylvania Press.
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenshark, G. G., & Little, T. D. (2015). Relationships between self-determination and postschool outcomes for youth with disabilities. *The Journal of Special Education*, 53, 30–41. doi:10.1177/0022466913489733
- Shogren, K.A., Wehmeyer, M.L., Little, T.D., Former-Pratt, A.J., Palmer, S.B., & Seo, H. (2017). Preliminary Validity and Reliability of Scores on the Self-Determination Inventory: Student Report Version. *Career Development and Transition for Exceptional Individuals*. DOI: 10.1177/2165143415594335
- Sinclair, J. (1993). Don't Mourn for Us. *Our Voice* 1(3). [https://www.autreat.com/dont\\_mourn.html](https://www.autreat.com/dont_mourn.html)

- Singer, A., Lutz, A., Escher, J. y Halladay, A. (2022). A full semantic toolbox is essential for autism research and practice to thrive. *Autism Research*. <https://doi.org/10.1002/aur.2864>.
- Singer, J. (1999). Why can't you be normal for once in your life? From a 'Problem with no Name' to a new category of disability. In *Disability Discourse*, Corker & French [eds]. Open University Press.
- Spiel, K., Frauenbergher, C., Keyes, O., & Fitzpatrick, G. (2019). Agency of Autistic Children in Technology Research – A Critical Literature Review. *ACM Transactions on Computer-Human Interaction*, 26(6): 1-40. <https://doi.org/10.1145/3344919>
- Swierstra, T. (2015). Identifying the normative challenges posed by technology's 'soft' impacts. *Nordic Journal of Applied Ethics* 1 (1):5-20. <https://doi.org/10.5324/eip.v9i1.1838>
- Syropoulou A, Vernadakis N, Papastergiou M, Kourtessis T. Psychometric evaluation of the Rosenberg Self-Esteem Scale in primary school students with mild intellectual disability: First evidence. *Res Dev Disabil*. 2021 Jul;114:103964. doi: 10.1016/j.ridd.2021.103964.
- van de Poel, I. (2016). An Ethical Framework for Evaluating Experimental Technology. *Science and Engineering Ethics*. 22: 667-686. <https://doi.org/10.1007/s11948-015-9724-3>
- van de Poel, I. (2020). Embedding values in AI systems. *Minds and Machines*, 30:385-409. <https://doi.org/10.1007/s11023-020-09537-4>
- van de Poel, I. & Royalers, L. (2011). *Ethics, technology, and engineering: An introduction*. Wiley-Blackwell.
- Vivanti, G. (2020). Ask the editor: What is the most appropriate way to talk about individuals with a diagnosis of autism? *Journal of Autism and Developmental Disorders*, 50(2), 691-693.
- UN General Assembly, Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assembly, 24 January 2007, A/RES/61/106, available at: <https://www.refworld.org/docid/45f973632.html> [accessed 30 October 2023]
- Webb, M.E., Fluck, A., Magenheim, J. et al. Machine learning for human learners: opportunities, issues, tensions and threats. *Education Tech Research Dev* 69, 2109–2130 (2021). <https://doi.org/10.1007/s11423-020-09858-2>
- Wehmeyer, M. L. (2005). Self-Determination and Individuals with Severe Disabilities: Re-Examining Meanings and Misinterpretations. *Research and Practice for Persons with Severe Disabilities*, 30(3), 113–120. <https://doi.org/10.2511/rpsd.30.3.113>
- Winkler, T., Spiekermann, S. (2021). Twenty years of value sensitive design: a review of methodological practices in VSD projects. *Ethics Inf Technol* 23, 17–21. <https://doi.org/10.1007/s10676-018-9476-2>
- Winter, J.A. (2003). The Development of the Disability Rights Movement as a Social Problem Solver. *Disability Studies Quarterly* 23(1): 33-61.

# Appendix:

## Ethical Reflection Team Meetings

### Introduction

As decided on 25-09-2023, Work Package 5 (WP5) of the Empower Project held three approximately one-hour, online and in-person meetings with representatives of all other Work Packages to discuss the draft version of WP5's first deliverable (5.1). These representatives, named below, have agreed to henceforth provide WP5 with feedback before the submission of subsequent deliverables as members of the Empower Project's internally established "Ethical Reflection Team". During each meeting, 2-3 members of other work packages commented on the draft version of 5.1 and offered advice on improving its scientific quality, language, and relevancy. WP5 has since incorporated this feedback into 5.1. This appendix outlines what was discussed during these meetings and how WP5 adapted 5.1 in response to representatives of other work packages' comments. The appendix represents a general characterisation of this process. Additionally, readers should note that WP5's first deliverable includes content based on suggestions that consortium members provided during meetings in Valencia, Nijmegen, and Cluj-Napoca (17-10-2022; 27-03-2023; 25-09-2023, respectively), which were not summarised in writing.

### **Ethical Reflection Team Members**

WP1 (Project Management) Gerardo Herrera, [gerardo.herrera@uv.es](mailto:gerardo.herrera@uv.es)  
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WP6 (Platform Impact) Christina Cotescu, [christina.costescu@gmail.com](mailto:christina.costescu@gmail.com)  
WP7 (Dissemination) Aurelie Baranger, [aurelie.baranger@autismeurope.org](mailto:aurelie.baranger@autismeurope.org)  
WP8 (Ethics Requirements, Gerardo Herrera, [gerardo.herrera@uv.es](mailto:gerardo.herrera@uv.es)

### Meeting 1 | 18.10.2023

**Attendees:** Gerardo Herrera WP1; Aurelie Baranger, WP7; Thomasin Coggins, WP5; Pim Haselager WP5.

**Location:** online

**Summary:** During the meeting, representatives of WP1 (Dissemination) and WP8 (Ethics Requirements) provided feedback on the draft version of 5.1. Gerardo Herrera commented that the deliverable should include a clearer explanation of the methods ethicists use to produce results. WP5 have amended the deliverable to reflect this concern and added a discussion of the main method they use, namely "the ethical cycle" and "value sensitive design" as described by van de Poel and Royakkers (2011), and Friedman & Hendry (2019) among others. This approach is highly influential within AI ethics and WP5 will use it to



organize its conceptual and consultation work. Additionally, Aurelie Baranger highlighted that WP5's deliverable draws heavily from the "the social model of disability" yet does not discuss another, more contemporary approach called the "the human rights-based model of disability". WP5 has now edited the deliverable to include a discussion on the latter approach (see section C1 "Individualization of Disability"). Aurelie Baranger also suggested that WP5 pay attention to yet-to-be-published surveys concerning AI use and autism conducted by the EUCAP. WP5 agreed to read these surveys once accessible.

### Meeting 2 | 23.10.2023

<sup>1</sup> Thomasin Coggins will join the Empower Project as a post-doctoral researcher for Work Package 5 in early 2024. She has yet to formally begin this position but has already contributed to deliverable 5.1.

**Attendees:** Aristides Ferreira, WP2; Christina Cotescu, WP6; Lucia Vera, WP3; Thomasin Coggins, WP5; Pim Haselager, WP5.

**Location:** online

**Summary:** During the meeting representatives of WP2 (Digital Education), and WP3 (Platform Development), and WP6 (Platform Impact) provided feedback on the draft version of 5.1. Christina Cotescu recommended that WP5 remove an example involving the barriers wheelchair users face while navigating built environments that do not include accommodating features (e.g., entry ramps or automatic doors) and replace it with one that highlights the disadvantages neurodiverse people experience - due to the Empower Project's focus on neurological rather than physiological disabilities. WP5 agreed and have added a more relevant example to the deliverable (see section C1 "Individualization of Disability"). Christina Cotescu also highlighted that the deliverable should include more up-to-date references, especially in section B1. WP5 have now added such references. Pim Haselager asked the other representatives if WP5 may access the results of the usability questionnaire used in Cluj-Napoca, which provides a first exploration of the experience of children who have played the games developed by the Empower Project. Pim Haselager highlighted that these results are important for WP5 as they contain data on how children perceive themselves. WP5 received access to a summary of these results, and they have been used in the deliverable.

### Meeting 3 | 23.10.2023

**Attendees:** Serge Thill, WP4; Marcos de Paula Bueno, WP4; Thomasin Coggins, WP5; Pim Haselager, WP5.

**Location:** Radboud University, Nijmegen, the Netherlands.

**Summary:** During the meeting two representative of WP4 (Platform Algorithms) provided feedback on the draft version of 5.1. WP4 are developing the algorithms used to interpret the empirical results generated by the Empower Project. Serge Thill noted that they use a hybrid approach (combining machine learning (ML) and manual coding) to create these algorithms, which allows for effective human oversight. Specifically, humans remain

explicitly “in-the-loop” as teachers supply the ground truth for AI algorithms by completing questionnaires once their students have played a game. Additionally, WP4 provides teachers with information concerning the range of uncertainty they should expect from the algorithms, thus enabling them to make informed, critical use of the analyses generated by WP4’s algorithms. Pim Haselager noted that this emphasis on the end user’s understanding of the limitations of AI is recommendable from an ethical perspective. Additionally, the attendees discussed how the somatic data collected by WP4 (e.g., students’ heart rate variability and galvanic skin responses) relates to the notion of empowerment. For instance, such data could indicate students’ stress levels, thus be used to triangulate the results produced by WP2, 3 and 6 concerning students’ evaluation of the games developed by the Empower Project. These data may provide valuable information concerning whether students feel empowered by such games and help WP5 develop ethical insights on what it means to be empowered (see Part A1 of deliverable 5.1).

**Conclusion:** Both authors of deliverable 5.1 (Pim Haselager and Thomasin Coggins) confirm that all three meetings were exceptionally valuable. The comments provided by representative of other work packages have helped WP5 to greatly improve deliverable 5.1. Most notably the meetings enabled WP5 to align its conceptual and theoretical work more closely with the research being conducted by other Work Packages (e.g. concerning AI implementations and data acquisition). Additionally, representative of other Work Packages identified many points of improvement within deliverable 5.1 that WP5 would not have discerned by themselves. WP5 aims to strengthen collaborative efforts like those that led to the completion of deliverable 5.1 during the next stage of the Empower Project.